

Emotional and physical demands on caregivers in home care to the elderly in Switzerland and their relationship to nursing home admission

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Background: Planning the home care of growing numbers of old, dependent people must include the caregivers' burden. **Methods:** A convenience sample of 129 caregivers of elderly patients with multiple diagnoses was interviewed about the caregiving context, burden, caregivers' tolerance of patients' troublesome behaviours and physical symptoms, mutuality and feelings of closeness between caregiver and patient. Continued maintenance of home care was assessed by a follow-up telephone call. **Results:** Caregivers were mainly spouses (67%) and female (73%), and the mean duration of care was 5.5 years. In five activities of daily living (ADL) 50–69% of the patients needed full help. Caregivers reported predominantly negative effects of caregiving on their physical and mental health, rest and sleep, leisure time and social life, problems with patients' symptoms and behaviours and little or no conversing (51%) or exchanging feelings with patients (71%). **Predictive models:** Contributors to variance were for burden (35%), impact of care on caregivers' mental health, social relations and leisure time, patients' gender, accumulation of patients' symptoms and behaviours; for caregivers' tolerance toward patients' symptoms and behaviours (17%) caregivers' physical health, patients' level of confusion, feelings of mutuality; for mutuality (22%) and for closeness (19%) caregivers' mental health, patients' accumulation of symptoms and behaviours. Within 23 months 19% of the patients had been institutionalized. Factors giving a higher likelihood of institutionalization were: being male, caregiver was not a partner, and less closeness between caregiver and patient. **Conclusion:** Caregiving of older persons has bio-psychosocial ramifications for caregivers. Closeness between caregiver and patient seems to be a key factor in determination of the long-term outcome.

Keywords: caregiver burden, caregiver tolerance of patients' symptoms and disturbed behaviours, caregiving, home care of elderly in Switzerland, institutionalization

In Switzerland, as in other industrialized countries, a dramatic increase in the proportion of the elderly in the population is predicted over the next 20 years, due to a fall in birth rates and lower mortality rates.¹ With the ageing of the population, morbidity and disability will also increase.^{2,3}

In 1990, persons aged 60 and over constituted 14.4% of the total population in Switzerland. In 1992/93, 7.7% of the population aged 60 and above were cared for at home due to diverse disabilities^{1,4} primarily by older women.⁵ It has been estimated that the unpaid care work amounts to 10–12 billion CHF (approx. 6.6–8 billion US\$) annually.⁶

Research on caregiving highlights two coexisting realities for caregivers: negative experiences such as burden, strain, depression and health deterioration, and, on the other hand, positive experiences like feelings of mutuality, gratification and finding meaning in the care. Both realities are thought to influence the continuation or breakdown of caregiving at home.^{2,7–11} Most research on caregiving has been done on caregivers of patients with dementia since this care is perceived to pose the most extreme challenges to the carer.¹²

A certain amount of burden is part of all caregiving situations. Increased burden may be expected when caregivers are women, probably due to more emotional involvement and enmeshment with the patient;^{13–16} in situations with high ambiguity related to the patient's changed personality;¹⁷ when caregivers perceive the illness trajectory of the patient to worsen^{9,18} and when losses in their social life, family relations and leisure activities occur.^{2,16}

Caregivers' tolerance is lower when troublesome behaviours and/or physical impairments are present. Faecal and urinary incontinence, instability and falls, sleep disturbances and

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communication difficulties are frequently mentioned as posing major problems for caregivers.^{2,12,18-20}

Predictors of caregivers' tolerance for care include progression of care over time,¹³ the caregivers' skilfulness in handling tasks,²¹ mutuality and good relationships between caregiver and patient as well as overall social resources.^{16,18,22,23} Most researchers agree that, in addition to caregiver burden, the onset and/or exacerbation of troublesome behaviours^{2,24-31} contribute to institutionalization. Another major factor leading to discontinuation of home care is the growing dependency on caregivers for activities of daily living (ADL), especially in the realm of bowel and bladder functions^{19,32-34} and the need to increase time invested in care.³⁵

Comprehensive home care policies are clearly needed to prevent deterioration of caregivers' health and breakdown of family structures, and to maintain autonomy and optimal quality of life for the patient and family.³⁶

METHODOLOGY

The convenience sample for this study comprised 129 caregivers of frail and incapacitated elders. It included two groups of caregivers. The first group of 33 caregivers took part in a randomized study of the effects of home visits for disability prevention in community dwelling elderly³⁷ and the second group of 96 caregivers were recruited by community nurses as meeting the study criteria.

To be included in the study the caregiver must have been the prime caregiver for a patient at home for at least four days a week for at least 3 months, and speak German. Patients had to be at least 60 years old, suffer from a chronic health condition and be dependent on another person for help in at least three ADL.

Out of 150 caregivers who were approached, 21 (14%) refused to participate because they did not identify themselves as caregivers, had been participating in interviews for another study, or felt pressed for time.

The 129 who consented to participate were interviewed in their homes, in most cases separately from the patient.

VARIABLES AND THEIR MEASUREMENT

The data collection instrument was a structured interview in six parts: demographic data; health and illness variables of the caregiver and patient; caregiving context and three scales measuring the dependent variables: care giving burden; capacity to tolerate symptoms and behaviours; and mutuality and closeness between caregiver and patient.

■ ADL scale

The ADL scale included nine activities – eating, body care, mobility, voiding including one item on help needed in taking medications. Caregivers were asked to indicate whether the patient needed no or little help (score 0), or complete help (1). The IADL scale measured help needed by caregivers in activities such as cooking, cleaning and shopping. Caregivers were asked to indicate activities they needed no or little help (score 0), or full help (1). Both scales were translated and modified from the 'OARS' Multidimensional Functional Assessment Questionnaire.³⁸

■ Burden scale

The Burden scale was constructed for a study of family care for severely handicapped children and older persons in Israel.¹⁸ The ten-item scale covers impact on: i) physical and mental health, ii) ability to meet personal needs such as privacy, free time and work, iii) relationships with family and others, and iv) the relationship with the patient. For each item the caregiver was asked to indicate whether he/she felt the impact of caregiving was negative (increase in burden, score 1), or there was no impact (score 0), or a positive impact (decrease in burden, score -1). Krulik et al.¹⁸ reported high face validity and internal reliability (Cronbach's alpha = 0.75). The tool was translated from English into German using the 'back translation method'.⁴⁰ Following a pilot study impact on privacy was omitted. Impact on work was excluded since the majority of the caregivers were retired. Because changes were made in the original scale, principal components factor analysis was performed and yielded two main factors. Factor 1, the impact of care on the caregiver's personal life, explained 28.7% of the variance and factor 2, the impact on his/her social life, explained 17.8% of the variance. The impact on relationship to the patient did not fit either factor.

■ Symptoms and behaviours tolerance scale

The Symptoms and behaviours tolerance scale was also developed for the Israeli study¹⁸ to record various symptoms and behaviours of the patient and the caregiver's perceived tolerance of these. The authors report high face validity and internal reliability (Cronbach's alpha = 0.75). This scale was also translated by the back translation method.³⁹ Based on the pilot study, the item 'dangerous behaviour' was deleted from the scale. The final 20-item scale used included seven items related to physical impairments such as incontinence, instability, problems with vision, and hearing impairment, and 13 items related to behaviours such as violence, nagging, depressed mood and unwillingness to get out of bed. Caregivers were asked to indicate i) whether the symptoms and behaviours existed in their patients, and ii) if yes, how difficult it was for them to deal with them. For this study two scores were constructed: one summed the number of symptoms/behaviours present and the second represented the tolerance ratio (ratio of the number of symptoms/behaviours scored as very problematic or intolerable to the number of symptoms/behaviours present).

■ Mutuality scale

The Mutuality scale was constructed for the present study, defining mutuality as activities shared by caregivers and patients. The scale was composed of six items describing the frequency (never 0, seldom 1, quite often 2, very often 3) of shared activities like playing games, watching television, exchanging feelings, and going out; and one item measuring the frequency of feeling closeness between caregiver and patient. The score consisted of the sum of the frequencies (0-18). A test for internal reliability produced an adequate reliability (Cronbach's alpha 0.65).

■ Institutionalization

Between 12 and 23 months after the initial interview,

respondents were asked by phone whether or not the patient was still cared for at home. In cases where caregiving at home had been terminated, they were asked the reasons for this change. Referrals to nursing homes and long-term hospitalization on geriatric wards counted as institutionalization.

■ Statistical methods

Apart from tabulations, the statistical methods used included ordinary and logistic multiple regressions.

RESULTS

Demographic data

Demographic data of the caregivers and patients and perceived physical and mental health of the caregivers are displayed in *table 1*.

In addition, more than 50% of the caregivers reported experiencing either headaches, back, shoulder, arm or leg pains or a combination of these; 53% suffered from sleep disturbances; 39% suffered from lung and or heart problems; and 19% from gastrointestinal dysfunction; 26% reported memory impairment.

Information on patients' health was taken from medical and nursing records. The majority of the patients had more than one diagnosis, some had up to five; 33% had impaired mobility after stroke, amputation etc., 25% suffered from memory impairment or dementia, 13% had Parkinson's disease, 12% severe heart problems, 6% progressively deteriorating neurological diseases, while 5% suffered from cancer and 4% from depression.

Caregiving context

The mean duration of care was 5.5 years (range: 3 months to 41 years); 68% of the caregivers spent more than 12

hours per day in caregiving and 56% were getting up to give care at night. Caregivers' perception of patients' need for help in ADL are presented in *table 2*.

Complete help was needed in 45–69% of these care situations for body care, dressing, excretion and mobilization, while each fifth patient needed to be fed. When caregivers were asked to predict the patient's illness trajectory, 62% thought it would worsen, 15% said it might stay the same, 19% perceived it to fluctuate and only 4% believed the condition would get better.

As for the caregivers themselves, 38% needed no help with IADLs; however, 69% mentioned receiving some help from family and friends. Few (21%) took advantage of respite care during vacations, and even fewer (7%) used a day care centre for the patient.

Burden, tolerance and mutuality

Table 2 presents the impact of care giving on the personal and social life of the caregivers and on their relationship with the patient. As can be seen from the table, a majority of these caregivers perceived their mental health, rest and sleep as well as their leisure time to be negatively affected by caregiving. For some, feelings of self-confidence and, in certain families, relationships were positively affected. The tolerance and ability to manage various symptoms and behaviours for the caregiver are summarized in *table 3*.

The highest number of caregivers in this study ranked instability/falls and impaired communication as the most difficult symptoms to deal with. Restlessness at night, confusion, and wandering/getting lost were behaviours presenting great difficulties to every second caregiver who was confronted with them. The tolerance ratio for the

Table 1 Caregiver and patients' demographics

Variables		%	n	Mean	SD	Range
Caregivers						
Age	Years			69	12.4	36–97
Gender	Female (2)	73	94			
Relationship to patient	Spouses	67	87			
	Children	26	33			
	Others	7	9			
Living in same household with patient		89	115			
Highest education	Compulsory school	26	34			
	Apprenticeship	47	60			
	Professional education	27	35			
Financial situation (N=127)	(Rather) good	86	109			
	(Rather) poor	14	18			
Perceived physical health	(Very) good (0)	60	77			
	Medium (1)	32	41			
	(Very) poor (2)	9	11			
Perceived mental burden	No/little (0)	60	77			
	Medium (1)	20	26			
	Quite/very much (2)	20	25			
Patients						
Age	Years			82	8.2	61–99
Gender	Male (1)	48	62			
	Female (2)	52	67			

different symptoms and behaviours for these caregivers was 0.4 (SD 0.3). A tolerance ratio of zero indicates that no symptoms/behaviours present are perceived as problematic, while a tolerance ratio of one means that all symptoms/behaviours are problematic.

Activities shared by caregivers and patients representing mutuality are presented in *table 4*, which shows that every second caregiver had little or no conversations with the patient and two-thirds reported little or no closeness between themselves and the patient.

Institutionalization

Follow-up telephone calls were made between 12 and 23 (mean: 19.2) months after the interview. They revealed that home care had been terminated in 54 (42%) of situations. Of these, 42 patients had died, 17 after they had been hospitalized or moved to a long-term care facility (13 died within three months of their admission) and 25 at home. At the time of the phone call, 12 patients were still in a long-term care institution.

The main reasons for the institutionalizations reported by the families were: i) the caregiver could not continue to care (feeling overburdened, needing to hold a job, had died) ($n=11$); ii) the patient's health deteriorated ($n=6$); and iii) the health of both the caregiver and patient deteriorated ($n=7$).

Predictive models

In the second stage of data analysis stepwise regression was used to determine whether and to what extent the independent variables (demographics, health and illness

Table 3 Presence and tolerance of patient's symptoms and behaviours (ranked by difficulty to manage)

	Percentage present in total sample	Percentage experienced as very problematic or intolerable in situations where present
Symptoms		
Unstable, falls	70	61
Impaired understanding	48	50
Impaired talking	43	47
Impaired vision	47	43
Incontinence	60	39
Problems with bowel movement	44	39
Sleepless, poor sleep	59	36
Behaviours		
Restless at night	35	53
Confused	44	52
Wandering, getting lost	16	50
Aggressive	29	46
Disinterested	38	45
Depressive, cries	50	45
Forgetful	70	43
Ungrateful	20	42
Suicidal	8	40
Nagging	36	38
Restless during day	32	37
Violent	9	27
Unwilling to get out of bed	18	22

Table 2 Levels of help needed in patients' activities of daily living (ADL) and medication and impact of care on caregivers' personal life, relations and relationship to the patient (ranked by need for full help and negative impact)

	No help		Little help		Full help	
	%	n	%	n	%	n
Patients' ADL						
Medication	9	11	8	10	83	104
Body care	10	13	21	27	69	89
Dressing	11	14	29	38	60	77
Voiding	34	44	16	20	50	65
Getting out of bed	31	40	19	25	50	64
Bowel movement	36	47	14	18	50	64
Walking	19	24	34	44	47	60
Transfer bed to (wheel)chair	40	51	15	20	45	58
Eating	35	45	45	58	20	26
	Negative		No impact		Positive	
	%	n	%	n	%	n
Impact on caregivers'						
Personal life						
Mental health	55	71	36	47	9	11
Rest and sleep	55	71	43	56	2	2
Physical health	47	61	51	65	2	3
Sense of confidence	12	15	57	73	31	39
Relations						
Leisure time and social life	80	103	17	22	3	4
Relations friends	38	49	57	73	5	7
Family relations	16	21	61	79	23	29
Relationship to patient (N=128)	36	46	38	49	26	33

variables, caregiving conditions) explained the variance in the dependent variables caregiver burden, tolerance ratio, mutuality and closeness. Mutuality was also used as an independent variable to predict the tolerance ratio and closeness and closeness also for predicting mutuality. In the regression procedure non-significant independent variables were removed step by step, so that in the end only the significant variables were kept for each dependent variable. Table 5 shows the predictive variables for each of the dependent variables.

Burden

Thirty-five per cent ($R^2=0.352$; F-test: $p>0.0001$) of the variance in caregiver burden was explained by the patient's gender, the sum of the patient's symptoms and

behaviours, the caregiver's perceived mental health, his/her need to get up at night, and the impact of caregiving on his/her relationships. Burden was less if the patient was female, and presented fewer difficult symptoms and behaviours, the caregiver perceived his/her mental health to be better, needed to get up less at night and his/her relations with other people were less negatively affected by caregiving.

Tolerance ratio

Eighteen per cent ($R^2=0.177$; F-test: $p>0.0001$) of the variance in the tolerance ratio was explained by the independent variables. Caregivers were more tolerant towards the patient's symptoms and behaviours if they perceived their physical health to be better, if the patient was less confused and if they shared more activities with the patient.

Mutuality

The relationship to the patient and the sum of the patient's symptoms and behaviours explained 22% ($R^2=0.216$; F-test: $p>0.0001$) of the variance in mutuality represented by shared activities with the patient.

Closeness

Furthermore, 19% ($R^2=0.194$; F-test: $p>0.0001$) of the variance of closeness were explained by shared activities and mental health of the caregiver.

Institutionalization

Finally, logistic regression was performed to determine whether the independent variables predicted institutionalization. The final regression model is also presented

Table 4 Frequencies of shared activities by caregiver and patient (ranked by frequency) and feelings of closeness

Shared activities	Never or seldom		Quite or very often	
	%	n	%	n
Going out	91	117	9	12
Play games	88	114	12	15
Walking	72	93	28	36
Exchange feelings	71	91	29	38
Conversing with each other	51	66	49	63
Watching TV, listening to radio	39	50	61	79
Feeling close (N=125)	66	82	34	43

Table 5 Predictive variables for burden, tolerance ratio, mutuality, closeness and institutionalization

Dependent variables	Independent variables	Coefficient	SE of coefficient	p-value ^a
Burden	Care impact on social life (0=negative, 1=no, 2=positive)	-0.196	0.097	0.0449
	Sum of symptoms and behaviours (1-20)	0.086	0.034	0.0128
	Caregiver mentally burdened (0=no/little, 1=medium, 2=much/very much)	0.287	0.103	0.0062
	Getting up at night (0=no, 1=yes)	0.759	0.229	0.0012
	Patient's gender (1=male, 2=female)	-0.648	0.230	0.0057
Tolerance ratio	Mutuality (6 items: 0=never, 3=very often)	-0.015	0.007	0.0295
	Caregiver's physical health (0=very good/good, 1=medium, 2=bad/very bad)	0.087	0.029	0.0033
	Patient's confusion (0=not confused, 1=confused)	0.115	0.051	0.0246
Mutuality	Closeness (0=never, 3=very often)	1.226	0.295	0.0001
	Sum of patient's symptoms and behaviours (1-20)	-0.265	0.083	0.0019
Closeness	Mutuality (6 items: 0=never, 3=very often)	0.103	0.023	0.0001
	Caregiver mentally burdened (0=no/little, 1=medium, 2=much/very much)	-0.191	0.073	0.0100
		Odds ratio	95% CI	p-value
Institutionalization	Patients' gender (female versus male)	0.193	0.048-0.765	0.0193
	Partner (caregiver is partner versus caregiver is not partner)	0.173	0.043-0.693	0.0132
	Closeness (0=never, 1=some times, 2=often, 3=very often)	0.593	0.340-1.034	0.0654

a: Regression-based test for the hypothesis of no association of the dependent variable with the independent variable in the same line of the table
95% CI: 95% confidence interval

in *table 5*. The probability of being institutionalized was greater when the patient was male, when a non-spouse/significant other was the prime caregiver, and when the caregiver and patient were less close.

DISCUSSION

Caregivers' gender, affinity to the patient and living arrangements were comparable to caregivers in some larger European studies.^{2,11} However, more caregivers in this sample (60%) declared themselves to be in good to very good physical and mental health, when compared to other European studies.^{16,18} Similar percentages of perceived good health were reported by Meier and Ermini-Fünfschilling⁴⁰ among 76 Swiss caregivers of demented family members. These figures also represent the perceived general health status of the elderly in Switzerland.^{1,4} The discrepancy between Swiss and other European percentages of ill health may be explained by cultural differences in reporting self-assessed health and psychological disturbances.

The percentage of caregivers who reported their patients as needing help with activities of daily living was considerably higher in our study than in the European studies assembled by Jani-Le Bris,² but was comparable to Grässel's¹¹ findings from a sample of 1911 German caregivers. The tendency towards higher dependence may be due, in part, to our study's inclusion criteria, which favoured the selection of participants caring for highly dependent patients.

The data on burden suggest that these Swiss caregivers, like their European and North-American counterparts, experienced high levels of burden with negative effects on their physical and mental health, their rest and sleep, leisure time activities and social relations, as well as their relationship to the patient. Burden was higher when the patient was male, exhibited more physical dysfunction and troublesome behaviours, the caregiver perceived his or her mental health to be more strained and the caregiver had to get up at night. These findings emphasize that burden is inherent in all caregiving situations, across illness characteristics and cultures and that burden increases caregivers' vulnerability to ill health, depression and isolation.^{2,9,10-12,16,40}

Two patients' physical impairments and three behaviours were reported to be problematic or intolerable by 50% or more of the caregivers in this study. The most difficult symptoms and behaviours to tolerate were those which necessitated the caregiver's constant presence and supervision, such as instability and falls, restlessness at night as well as wandering and getting lost. Impairments which hampered communication and mutual understanding and attested to personality changes, such as confusion and impaired communication were also hard on caregivers. The literature mentions these behaviours and symptoms as major causes for caregiver depression,¹² and increased uncertainty in relation to who the patient is,¹⁷ and as augmenting burden by restricting leisure and social activities.¹⁶ Higher tolerance levels of the caregivers in this study were partially explained by better physical

health of the caregiver, less patient confusion and more mutuality, as represented by shared activities.

However, a high percentage of the caregivers reported no or very little communication, exchange of feelings and feelings of closeness with the patient. Corbin et al.⁹ and Jani-Le Bris² alluded to the phenomenon that with patients' declining cognitive abilities and with time, caregivers tend to share difficulties with the patient less and less, let him or her participate less in decisions concerning their care and keep their feelings and growing resentment more to themselves. All of these may lead to a loss of closeness and higher levels of loneliness.

Studies on dementia have reported of 40% and above institutionalizations within a year.^{27-29,41} In this study 19% of the patients were institutionalized within two years of the interview. This discrepancy is not surprising, since our study group comprised patients with multiple diagnoses as opposed to only patients with dementia for whom home care may be more difficult to continue. The reasons given for institutionalization by Swiss caregivers are similar to those reported in the literature.

Institutionalization was more likely in this study if the patient was male. Women were found to be at higher risk of placing their care recipient in institutions, because they may have been psychologically over-involved and have a harder time setting boundaries in relation to time, self, and other roles.^{13,22,29,42} Being cared for by someone who is not a partner or spouse was another predictor of placement. Spouses and partners, having had a longer mutual history, may continue care out of a greater sense of moral duty or commitment.^{34,43} Furthermore, less closeness tended to lead to care termination. Closeness may be understood as an indicator of the caregiver's relationship to the patient. Quality relationships are considered crucial for the continuation of care.^{9,11,22}

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